



GOLD SPADE WINNER 2021

# THE TRANS CHILDREN

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WINNER OF THE GOLDEN SPADE 2021 IN THE ETERMEDIA NATIONAL DOCUMENTARY CATEGORY

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**CATEGORY**

Etermedia's documentary

**PARTICIPANT**

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**IN ADDITION TO THE ABOVE, THE FOLLOWING PEOPLE PARTICIPATED**

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**WHERE WAS THE JOB POSTED?**

[SVT Task Review \(https://www-fgj-se.translate.goog/guldspaden/redaktion/svt-uppdrag-granskning? x tr sl=sv& x tr tl=en& x tr hl=en& x tr\\_pto=sc\)](https://www-fgj-se.translate.goog/guldspaden/redaktion/svt-uppdrag-granskning? x tr sl=sv& x tr tl=en& x tr hl=en& x tr_pto=sc)

## **BRIEFLY DESCRIBE WHAT THE GRAVE REVEALED**

\*Children and young trans people have suffered serious side effects and injuries after hormone treatments at Karolinska Hospital. \*Despite the fact that doctors at the hospital knew about the injuries, they have not disclosed this to the outside world. \*The hospital has stopped new hormone treatments for children, but referred to potential side effects, despite seeing that the treatments caused real damage. \*After our publication, the National Board of Health and Welfare completely changed its knowledge support and now writes that "the risks outweigh the benefits", concerning hormone treatments for minors. \*Because diagnosis and treatment are carried out in different clinics, follow-up and responsibility in some cases fall between the chairs.\*Parents and children have not received any information about risks. \*Through extensive research, we were able to prove that there are at least 13 children who received serious, sometimes permanent damage from the treatment. \*When injuries were discovered, the hospital failed to write a deviation report or utrex< the injuries according to Lex Maria (however, this happens after UG's disclosure).

## **IN WHAT WAY DO YOU CONSIDER THAT THE DIG MEETS THE CRITERIA FOR A GOLDEN SPADE?**

Obtaining evidence that young patients have been harmed by a treatment is almost impossible if the care at the same time obscures what has occurred. It has required extensive and challenging research, where we turned over every stone imaginable, tracked down reports and discrepancies, and spoke to a wide range of sources who confirmed and provided additional information that corroborated our story. We have been able to tell that an already fragile and vulnerable group; young trans children, suffered serious side effects but that doctors wanted to cover this up, even though young trans people should have the same right to safe care as everyone else. Our report has had major consequences: After publication, the National Board of Health and Welfare postponed the launch of its new knowledge support for two months. (was to be published at the beginning of December) In what was then published on February 22, the authority makes a complete reversal: they write that the risks of treatment outweigh the benefits and that treatment should only take place in "exceptional cases". There is a big difference to the proposal that went out for consultation last autumn; where hormone treatments of minors were recommended. In addition, it had consequences in healthcare, where KS after the publication started its own review to improve the care of young trans people. After the review, the hospital has reported itself in the Leo case (our main case) according to Lex Maria and points to continued high risks of young trans people being harmed by the treatments. This is now being investigated by IVO. In addition, it had consequences in healthcare, where KS after the publication started its own review to improve the care of young trans people. After the review, the hospital has reported itself in the Leo case (our main case) according to Lex Maria and points to continued high risks of young trans people being harmed by the treatments. This is now being investigated by IVO. In addition, it had consequences in healthcare, where KS after the publication started its own review to improve the care of young trans people. After the review, the hospital has reported itself in the Leo case (our main case) according to Lex Maria and points to continued high risks of young trans people being harmed by the treatments. This is now being investigated by IVO.

## **HOW DID THE ORIGINAL IDEA FOR THE PROJECT ARISE?**

In connection with Astrid Lindgren's Children's Hospital (ALB) deciding in May 2021 to stop all new hormone treatments for children, a mother spoke up: her young trans son Leo had received treatment with stop hormones at ALB for four and a half years without some checks done. (Recommended maximum time is two years.) The treatment had caused serious damage to several vertebrae and Leo had been diagnosed with osteopenia, he had remained in the plant and suffered other injuries that doctors judged to be permanent. He has back pain all the time and can't stand up for more than 15-20 minutes. While doctors at the hospital were aware of Leo's injuries, the executives spoke on TV of "potential" risks with the treatment as the reason for the treatment stop. Parallel to getting to the bottom of Leo's and his family's case, the thought arose: Are there more children and young people who have been affected and that the healthcare system does not tell you about? Herein lay the major research challenge in the project. We hoped to find another 2-3 cases, but received twelve confirmed cases of serious side effects in children and young people, in addition to the case of Leo. All involved minor children who received puberty-blocking treatment, or hormone treatment, and where the hospital discovered injuries caused by the treatment. Even the hospital doesn't know how many there are, because they don't write deviation reports when side effects are discovered, which we also revealed. All involved minor children who received puberty-blocking treatment, or hormone treatment, and where the hospital discovered injuries caused by the treatment. Even the hospital doesn't know how many there are, because they don't write deviation reports when side effects are discovered, which we also revealed. All involved minor children who received puberty-blocking treatment, or

hormone treatment, and where the hospital discovered injuries caused by the treatment. Even the hospital doesn't know how many there are, because they don't write deviation reports when side effects are discovered, which we also revealed.

## **WHICH WORKING METHODS WERE APPLIED?**

For several years, we have reviewed trans care, which has led to a series of reviews from authorities: The National Board of Health, the National Medical Ethics Council and the National Committee for Medical Evaluation have all surveyed the research base on which the care is based and have found it to be very deficient. There are few studies and in principle no long-term studies at all on the new group of children and young people who are treated today. For this report, we have continued to review how the healthcare system relates to it, as well as how the various healthcare units in Sweden have acted after Karolinska University Hospital stopped new treatment efforts for children. The fact that side effects and irreversible damage were discovered and not reported - has shaken care units in Sweden, and had an impact and was debated internationally. Through our reviews, it has emerged that for several years trans care has been based on weak scientific support, there is a lack of long-term quality registers and follow-ups, as a result children and young people have suffered irreversible damage from the treatment, without the health care reporting about it. The working method has been decisive for the disclosure - both through our own compilations of public statistics, research on research documents, numerous in-depth interviews with those concerned within the profession, but also through unique source work. In this case, it has been decisive and the importance of good and lasting source work cannot be emphasized enough. A job that spanned a long time. Many of the sources that were decisive are people we have been in contact with for several years. By staying in touch and continuing to build trust even after publication, the contact has deepened and proved to be extremely important in the process and for this disclosure. When we started, no one knew how long, from what age and how many people received puberty blockers and sex-affirming hormones. It is not possible to read out, for example, the length of treatment; first discharge, last discharge etc from the open drug database. We ordered a unique register run from the National Board of Health and Welfare, which took several months to obtain. When it finally arrived (and after a number of modifications to the order itself), it showed that 87 young people had received stop hormones for three years or more. (Although according to available research material it should not be given longer than a maximum of two, if damage is to be avoided) We have also searched in Swedish and international drug databases and deviation reporting systems, where we obtained several important documents that both confirmed that the injuries are present in more patients, and were able to see that information about the risks was available. We have used international media archives and found that American patients who received puberty blockers for endometriosis and short stature suffered the same injuries as Leo. We have requested deviations from all regions, for the patient group. (It turned out that only Stockholm reported deviations on injuries, the other regions considered them to be expected and did not report them) We have also requested and received deviations that were sent to the Swedish Medicines Agency. Through the appeal to the BUP, where we were ultimately right (see below under problems), we gained access to additional information that confirmed more cases. Research in social media: many young trans people testify to serious side effects of hormone treatments, which are neglected by the healthcare system. It has been a balancing act, where it has been important for us to respect the integrity, even in the research phase, of the group that is already exposed. In this research, we got confirmation that the problem is widespread, although it did not give more confirmed cases to the report (to qualify as a case, we had the criterion that the healthcare itself must have described it as serious side effects caused by the treatment, deviations or medical records.) We have also read a lot of research reports; searched medscape for an overview, UK NICE review, as well as nhs.uk. We have also spoken to a number of researchers, both in Sweden and internationally. We requested and went through all emails between and to/from relevant managers/doctors at Karolinska, where we also got confirmation that they were asked to report what happened to Leo. It was still not done until we revealed what had happened and told us that the hospital covered up the injuries.

## **WHICH SOURCES WERE USED?**

Databases; FDA Adverse Event Reporting System, Medicines database, Diagnosis database, EMA Adverse events database, National Board of Health and Welfare's register service Official documents (such as treatment recommendations, research overview, etc.) Research reports NICE and nhs.uk - British compilations of the research data Many secret oral sources Many secret written sources Email extracts

## **WHAT PROBLEMS ARISED?**

It was difficult to get information from BUP and ALB. It became a game of cat and mouse, where we knew about reports, deviations and documents, but where repeated requests were required for the BUP to even confirm its existence. It later turned out that there were a number of deviation reports, but important information in these was blacked out when we got them out. By appealing confidentiality decisions and being upheld, we were able to access reports that confirmed more injuries to transgender youth. Several in the trans movement were concerned that our review would lead to poorer access to care and called for a boycott of the program. This meant that several young trans people who wanted to talk about their problems withdrew. Some activists also launched a social media campaign against us, where they hung out and painted Carolina black.

## **HOW MUCH TIME DID YOU SPEND?**

About six months.

## **WHAT REACTIONS HAS THE WORK RECEIVED?**

The National Board of Health and Welfare had ongoing work on developing new treatment recommendations for the care of young people with gender dysphoria. It was supposed to be published in early December, but after our report it was postponed until February 22. The new recommendation is a complete reversal from the proposal that was sent out for consultation in the autumn. The authority now writes that "the risks outweigh the benefits" and that treatment should only take place in exceptional cases. In the previous knowledge support it was stated that "the treatment is safe and secure". After our report, Karolinska began an investigation which has so far led to a LexMaria report. BUP also filed a non-compliance report on Leo after our accountability interview, where we raised the case and the issue. Leo and his family have been called to a meeting with responsible managers at Astrid Lindgren's Children's Hospital and received an apology.

## **HAS THE PROJECT BEEN REPORTED TO THE PO, EXAMINATION BOARD OR ANOTHER AUTHORITY?**

Yes, to the board of review but has been freed.



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